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ABSTRACT

A survey involving 330 parents investigated factors influencing parental decision making in the choice of services for children with developmental disabilities and assessed the consequences of the decision made at both the institutional and individual levels within particular family, neighborhood, and community networks. Data collection procedures included correspondence and discussion with state and local agencies and with individual facilities and parent clients; contact with parents through the school districts, regional program, and other facilities; and mailing out a 57 page survey questionnaire to over 400 families. Survey results were analyzed in terms of personal support networks and professional services, satisfaction with quality of professional services, parents' needs and resources, and perceived adequacy of community resources. Among findings were that many needs of parents are met by family, friends, and other parents; that parents are highly satisfied with the quality of the services they are currently receiving; and that, though relatively few have personal needs for which services are not available, most perceive a need for expanded community services. Tables with statistical data are included. (SBH)

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Parent Choice of Services for Children*

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Parent Choice of Services for Children

Abstract

This report is based upon research on the organization of services in the Illinois developmental disabilities system. Data from a mail survey questionnaire, completed by 330 parents in Lake County, is analyzed in terms of: personal support networks and professional services, satisfaction with quality of professional services, needs and resources, and perceived adequacy of community resources. Many needs for emotional support and information are met by family, friends, and other parents. Parents are highly satisfied with the quality of services received, report relatively few needs for which services are not available, yet perceive a need to expand community services.

This report is based upon work in progress on a multi-year project, funded for two years under the Extramural Research and Development Grant Program of the Illinois Department of Mental Health and Developmental Disabilities. Optimizing the use of community-based services by developmentally disabled persons is in keeping with the DMHDD policy of maintaining developmentally disabled persons in "normalizing" environments and with implementation of the provisions in Public Law 94-142 concerning placement in the least restrictive environment and parental involvement. In accordance with these policies, the long-range objectives of the project are: (1) to investigate factors influencing parental decision making in the choice of services for children with developmental disabilities, and (2) to assess the consequences of the decisions made at both the institutional and individual levels within particular family, neighborhood, and community networks.

During the first project year (1977-8), sample survey research data was collected on the process through which parents decide what type of assistance to obtain with the education and socialization of their developmentally disabled children. To accomplish this aim:

--a computerized review of the literature was produced including several hundred citations;

--a list of major subject areas was identified with an accompanying 87-page item pool;

--fourteen depth interviews, ranging from two to six hours in length, were conducted with families selected to provide variation in the nature of the developmental disability (mental retardation, autism, and epilepsy) and the age of the children for whom services were sought (14 months to 20 years old);

--a pretest of the mail survey questionnaire was conducted with families of children attending three schools (one public, two private) for the developmentally disabled in Evanston, Illinois, with completed questionnaires returned by 66 families (a 55% response rate);

--the final 57-page mail survey questionnaire was sent to all consenting Lake County, Illinois parents (approximately 500) of developmentally disabled children ages 0 to 21 years.

Work in progress during this second project year, 1978-9, utilizes the interview and survey data and continues the collaboration with Lake County service providers to accomplish three related specific aims:

--to develop a report investigating the relationship between family integration, community resources, and policy orientations towards normalization;

--to develop a handbook for parents and professionals listing resources and strategies for optimizing the development of developmentally disabled children; and

--to develop a model for research in similar areas with more complex populations and delivery systems.

This report focuses upon needs and resources as perceived by the parents themselves and reported in response to our mail survey questionnaire. The survey was undertaken because planning efforts for developmentally disabled services have addressed professional service providers' perception of need. However, the providers are not the group of people who make the original choice regarding the services needed by individual children and their families. It is the parents who act on the subjective and objective information available to them in order to secure care for their child. A great deal of decision making has already occurred before the service provider is introduced to the situation.

Lake County, Illinois was selected as the study site because the area has a diverse population and a wide range of services. There is a major state-operated residential center for severely and profoundly retarded persons and other smaller residential programs operated by private non-profit groups. The county is known for its comprehensive programs of special education offered through the public school districts. There are several sheltered workshop facilities for developmentally disabled

persons. Alternative residential programs, such as community living facilities for developmentally disabled persons, are beginning to be developed. The county contains people of a wide range of socioeconomic, ethnic, and racial backgrounds. Programs are relatively new and expanding. Therefore, Lake County provides an ideal situation in which to study parental decision making.

A third source of rationale for the approach to the problem relates to the timing of events in the proposed sample area. Various local efforts to plan services for developmentally disabled persons are mandated by the Developmental Disabilities Services and Facilities Construction Act (P. L. 91-517). In most areas of Illinois this planning effort begins at the sub-region level. However, within sub-regions 7/D.D. (Lake, Kane, McHenry, and part of Aurora Counties) the planning effort has been brought down to the county level. The most active county within this sub-region is Lake County. Many of the consumers and service providers in Lake County have become interested in developing a data base regarding the needs/wants of service consumers in their area. Because of this they are encouraging the conduct of research similar to that undertaken within this project. We have received complete cooperation from all relevant interests in Lake County.

Survey Data Collection Procedures

We began mailing the final survey questionnaire to Lake County parents who had signed a consent form agreeing to participate in the study on March 10, 1978. The population was defined as Lake County, Illinois, parents of developmentally disabled children ages 0-21 who receive services in Lake County. For the purposes of this study,

developmentally disabled is defined as children handicapped by mental retardation, cerebral palsy, epilespy, autism, or multiple handicaps involving one of the foregoing, and whose handicap required more than 50% time in a special educational program.

A. Locating the population.

1. Background. Extensive correspondence and discussion with agencies at the State and local levels, as well as with individual facilities and parent clients, resulted in the decision that almost all the population could be reached through public school districts because of P. L. 94-142, which states that, by 1980, all handicapped children, 3-21, be educated at public expense.

2. Principal networks for contacting parents.

a. School Districts. There are three special education districts serving Lake County.

--Waukegan District 60 Special Education. Developmentally disabled are served in special EMH and TMH classes in the public schools, in Lincoln Center (Waukegan) facility, or through private placements.

--Special Education District of Lake (SEDOL). Serves 41 school districts; developmentally disabled served at the Laremont School facility or through private placements.

--Northern Suburban Special Education District (NSSED). Serves the southeast portion of Lake County and the northeastern-most suburbs of Cook County. Developmentally disabled served in special EMH classes in the public schools, at Stratford Center facility, or through private placements.

b. Lake-McHenry Regional Program. Provides services for the 0-3

group in Lake and McHenry Counties, with the exception of the area served by NSSED above, who did not join the Program.

c. Other. A total of four families were contacted through two other facilities. Three letters were sent by the Moraine Association, which began construction in Spring 1978 of a community living facility for 18 and older; and one letter went out from The Lamb's, Inc., a private facility in Libertyville. All efforts to locate additional respondents not known to the school districts, such as through foster care agencies and nursing homes, were fruitless.

B. Contacting the population. Because of adherence to regulations governing rights of privacy, all mailings requesting parents to consent to participate in the survey questionnaire went out through the above four networks and the two facilities specifically mentioned above. All parents received a letter explaining the project and asking them to participate. If they were willing to do so, they were asked to sign a consent form and return it to the project headquarters at Northwestern University. Upon receipt of a consent form, a 57-page survey questionnaire was then sent out. A total of 330 usable questionnaires were returned (slightly over 400 families consented to participate from the approximately 700 families identified in the total population).

Characteristics of Respondents

Most (93%) of the questionnaires were filled out by the child's mother. In 78% of the families, the child's parents were married and living together. In 85% of the families the parents were white,

11% black, 3% Latino (with the remaining 3% other or no answer). With respect to education, about half (47%) had some college or advanced career training beyond high school graduation. Approximately 1/3 had yearly family incomes before taxes of less than $15,000, 1/3 between $15,000 and $25,000 and 1/3 over $25,000. Of their developmentally disabled children, 85% were diagnosed as mentally retarded with the disability being described as mild or moderate in approximately 2/3 of these cases.

Findings

From the perspective of a state-wide system a number of issues should be addressed concerning an evaluation of existing services. Four issues have been selected for discussion in this presentation: whether needs are being met by personal support networks or by professionals; whether parents are satisfied with the quality of current professional services; whether parents' needs are adequately being met by the personal support networks and services available; and whether community resources are perceived to be adequate.

Personal Support Networks and Professional Services

Significant others were utilized as sources of emotional support, as confidants (see Table 1) and as sources of information, as consultants (see Table 2).

Tables 1 and 2 about here

As might be expected, members of primary groups are frequently confided in when there are worries about the developmentally disabled child (husbands 88.8%, and friends and relatives 41.9%, being confided in often). What is

perhaps more interesting is that social service professionals also seem to be operating in this capacity traditionally associated with members of the primary group of extended family (48.5% often confide in social service professionals). Conversely respondents are least likely to confide in a rabbi, minister or priest, or to keep their worries to themselves.

When advice is sought, as might be expected, health service and educational professionals are those most likely to be talked to as "expert" sources of information (4/5 would talk to their child's doctor, or teacher, or principal). Again, what is perhaps more interesting is that parents are next most likely to talk to other family members or friends, choosing these primary group members as consultants ahead of organizations specifically concerned with their child's disability or other professionals such as social workers or psychologists. Least likely to be consulted for advice are librarians or staff members of a State governmental office. Underutilization of these information sources could result from either a lack of awareness of their expertise or availability, or from negative evaluations of the value to be gained from contacting these sources.

Satisfaction With Quality of Professional Services

In general, parents were satisfied with their children's current school or program (see Table 3). Questions concerning satisfaction with school personnel (not reported here) revealed that parents felt the staff were interested in their children as individuals and that teachers welcomed them as visitors.

Table 3 about here

A substantial majority (86.3%) of parents were satisfied with all

current medical professionals. The level of satisfaction was relatively similar regardless of child's age or type of disability, although families with higher incomes tended to be more satisfied.

Of the families who were currently dealing with one or more of the 13 types of social service professionals listed (N=194), 90% were satisfied. The younger the developmentally disabled child, the more likely parents were to be satisfied with social service professionals (preschool 100%, primary 89%, secondary 83%, transitional 82% satisfied). The less severe the mental retardation, the more likely parents were to be satisfied (mild retardation 100%, moderate retardation 91%, severe or profound retardation 85% satisfied). Parents of children with other types of disabilities reported: cerebral palsy 95%, epilepsy 78%, and autism 71% satisfied. There is no relationship between income and satisfaction with social service professionals.

Parents' Needs and Resources

Significant others, both primary group members and professionals, are utilized to meet the day-to-day management needs of caring for developmentally disabled children. (See Table 4.)

Table 4 about here

Child (day) Care. Personal resources--family, friends and paid sitters--are more likely to be used and perceived as necessary than are community resources--after school day care or respite care. Although needs are highest for younger children, over 1/2 of the families still use family and friends as babysitters for their adolescent children; approximately 1/3 still use paid sitters. All four types of child/day care

arrangements are used most frequently by families whose children are the most severely disabled (those with severe and profound retardation, cerebral palsy, and autism). The higher the family income, the more all four types of care are used.

Household Maintenance. Household assistance is relatively unavailable for the 10% of families who report that they need the service.

Self-Help/Therapeutic. Approximately 1/2 of families desiring self-help or professional counseling are currently using these services. The younger the developmentally disabled child, the more likely parents are to report that they use or would like to use both services, the informal and the professional. This could reflect either a learning effect, so that less support is necessary over time, or changing patterns of awareness and service availability. Parents of children with cerebral palsy and autism are most likely to use or want to use informal rap sessions; the reported need for professional counseling is not affected by the type of child's disability. Family income is not associated with the reported need for either service.

Information. There is a paucity of information sources utilized by families reporting such a need. The greatest need reported is for a parent manual (which will be one of the products from this research project), closely followed by the need for a referral service. Relatively high unmet needs are also reported for an ombudsman, and for professional and informal crisis lines. Age of child was associated only with need for an ombudsman and for a referral service. Reported need for an ombudsman increased with age of child, whereas need for a referral service was reported highest by parents of the youngest and oldest children. The more

severe the mental retardation, the more likely parents were to report needs for all five types of information sources. Needs for information sources reported by parents of children with cerebral palsy and autism were similar to those reported by parents of the severely and profoundly retarded.

Perceived Adequacy of Community Resources

A wide variety of community services are necessary to provide family support, educational and diagnostic programs, living alternatives, and general community acceptance. Of 19 specific services identified, only special education programs were perceived as adequate by as many as 50% of parents. Looking at the need for services another way, less than 1/5 perceived any of the 19 specific services as unnecessary. (See Table 5.)

Table 5 about here

Family Support. Family support services--babysitters, crisis lines, referral services, respite care, homemaker/home-health aides, and counseling --are perceived as extremely necessary but woefully inadequate. Only parent or family counseling services were perceived as adequate by as many as 1/3 of parents, with the other five specific services identified perceived as adequate by 10% or less. Conversely, only homemaker/home-health aides were perceived as unnecessary by as many as 20% of parents, with the remainder perceived as unnecessary by less than 10%. Parents of older children, of children with more severe disabilities, and with higher family incomes were more likely to favor expansion of family support services.

Educational and Diagnostic Services. Educational and diagnostic services are also perceived as extremely necessary, but as more adequate than

family support services. After-school day care is seen as the area where increased availability is most needed (by 82.0% of parents), and this is particularly the case for parents of younger children. The more severe the disability, the greater the perceived need for all four services listed. Family income is not systematically associated with perceived need for educational and diagnostic services.

Living Alternatives. Approximately 3/4 of parents perceive a need for expansion of community living facilities, residential facilities, and foster homes. Nursing home alternatives are perceived as most adequate (by 16.0% of parents), but even here approximately 2/3 of parents perceive a need for increased availability. Parents of transitional (19- to 21-year old) children, those who are most likely to have an immediate need to look for alternatives, report the greatest need to increase availability. The more severe their children's disability, the greater the parents' perceived need for increased living alternatives. In general, parents with higher family incomes perceive the greatest need for expansion of all 4 types of living alternatives; parents with low family incomes (less than $15,000 per year) similarly perceive a greater need, but for increased availability of foster care only.

General Community Services. Architectural adjustments, news media coverage, and expansion of library acquisitions are identified as the priority areas for service expansion. Religious services and special transportation are perceived as more adequate, but even here over 2/5 of parents report a necessity for expansion. The more severe their children's disabilities, the more likely parents are to perceive it necessary to expand services. Perception of need is not associated with age of child or

family income.

Discussion

It is interesting from a delivery-system perspective that so many needs of parents, for emotional support and for information, are met by family, friends, and other parents. These personal resources should be supported and complemented, rather than supplanted, by service providers.

Parents are highly satisfied with the quality of the services they are currently receiving. Relatively few have personal needs for which services are not available, yet the vast majority perceive a need for expanded community services. At least at the level of community services, parents realize the necessity for a wide range of services for developmentally disabled children, not limiting their idea of a community service system to their own particular needs.

Table 1. Confidents (sources of emotional support).
When you are worried about something concerning your developmentally disabled child, how often do you confide in each of the following? (rank ordered by frequency as source of emotional support)

	Often	Sometimes	Hardly Ever	
1. My husband	88.8%	9.8	1.4	N=276
2. Social Service professionals (school personnel, social worker, etc.)	48.5%	32.6	18.9	N=307
3. A friend or relative	41.9%	32.1	26.0	N=308
4. A doctor or other medical professional	39.0%	34.7	26.3	N=308
5. Other parents with developmentally disabled children	19.5%	30.3	50.2	N=297
6. No one; I keep it to myself	7.5%	12.2	80.3	N=295
7. A rabbi, minister or priest	4.7%	12.0	83.3	N=300

Table 2. Consultants (sources of information).
Parents often react differently to advice depending upon who gives it. If you had a serious decision to make about your developmentally disabled child, would you talk to any of the following? (rank ordered by frequency as source of information)

	Would	Depends	Would not	
1. Child's doctor	81.8%	12.0	6.1	N=308
2. Child's teacher or principal	79.3%	12.9	7.8	N=309
3. Other family members or friends	67.7%	15.7	16.6	N=300
4. An organization specifically concerned with your child's disability	63.8%	25.2	11.0	N=309
5. Other professional (such as a social worker or psychologist)	59.4%	27.1	13.5	N=303
6. Other parents with developmentally disabled children	40.4%	33.7	25.9	N=297
7. A priest, minister or rabbi	24.5%	24.2	51.4	N=298
8. Someone in a State governmental office	14.8%	26.6	58.6	N=297
9. A librarian	5.1%	8.5	86.4	N=294

Table 3. Satisfactions with Professionals Currently Being Seen About Child	
School or Program Personnel	
Satisfied	88.0%
Mixed feelings	6.3
Dissatisfied	5.7
	N=317
Medical Professionals	
Yes	86.3%
No	13.7
	N=314
Social Service Professionals*	
Yes	54.9%
No	6.3
Not seeing any now	38.8
	N=317

*This question appeared beneath a question asking parents about their contact with 13 types of social service professionals: speech therapist, physical therapist, occupational therapist, recreation therapist, vocational counselor, social worker, clinical psychologist, family, group or individual therapist, public health nurse, professional homemaker, nutritionist, house or foster parent, genetic counselor.

Table 4. Personal Sources of Support and Needs.
Do you use any of the following to help you take care of your developmentally disabled child?

	Yes	No, but would like to	No, do not need	
Child (day) Care				
Babysitting provided by family and/or friends?	65.7%	5.7	28.6	N=315
Paid babysitters?	47.1%	6.1	46.8	N=310
After school day care?	3.7%	11.3	85.0	N=301
Respite care provided by a residential facility?	7.0%	13.6	79.5	N=302
Household Maintenance				
Regular paid domestic help?	1.3%	11.8	86.8	N=304
Visits by a homemaker/home-health aide?	2.7%	7.0	90.4	N=301
Self-Help/Therapeutic				
"Rap" sessions with other parents of developmentally disabled children?	32.5%	25.6	42.0	N=305
Parent counseling and guidance?	17.7%	22.6	59.7	N=305
Information				
An informal "crisis line" with other parents of developmentally disabled children to provide support in an emergency?	5.9%	30.7	63.4	N=306
A "crisis line" supported by the State for contacting the necessary professionals in an emergency?	3.6%	40.4	56.4	N=305
A referral service funded by the State to provide help in finding services and programs when needed?	9.8%	55.2	35.0	N=306
An ombudsman to investigate complaints about services for the developmentally disabled?	4.3%	40.5	55.3	N=304
A parent manual that would identify local, state, and national services available and suggest ways to utilize them?	11.7%	61.8	26.5	N=309

Table 5. Community Resources.
Some parents are more satisfied than others with the services that are available to developmentally disabled children in their community. Thinking of your community, please rate the services below according to how important it is to expand or offer them: (rank ordered by need to expand or offer within each type of service)

	Adequate	Expand or Offer	Not Necessary	
Family Support				
1. Babysitters trained to handle developmentally disabled children	2.4%	92.5	5.2	N=291
2. Crisis lines for parents in times of stress	5.8%	88.7	5.5	N=292
3. Community referral service for legal, medical, and financial needs	10.5%	86.8	2.7	N=296
4. Respite care	8.9%	82.1	8.9	N=257
5. Homemaker/home-health aides	6.0%	74.2	19.8	N=283
6. Parent or family counseling services	32.6%	63.2	4.3	N=304
Educational/Diagnostic				
1. After school day care	3.9%	82.0	14.1	N=284
2. Early intervention programs	29.7%	66.5	3.8	N=290
3. Diagnostic services and clinic	31.4%	65.1	3.6	N=303
4. Special education programs	50.9%	49.1	0.0	N=316
Living Alternatives				
1. Community living facilities	14.1%	75.7	10.2	N=284
2. Residential facilities	14.5%	74.8	10.7	N=289
3. Foster homes	10.3%	71.9	17.8	N=281
4. Nursing homes	16.0%	65.1	18.9	N=281
General Community				
1. Architectural adjustments made so that it is easier for disabled people to get around	7.5%	89.3	3.1	N=292
2. Public education concerning developmental disabilities in the news media	7.8%	88.4	3.7	N=294
3. Reading materials in libraries on child's disability	23.4%	70.7	5.9	N=290
4. Church services	30.5%	55.1	14.4	N=292
5. Special buses or vans	43.0%	41.0	6.0	N=302